

REVIEW

Patient Perspectives on Medical Confidentiality

A Review of the Literature

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OBJECTIVE: To lay the groundwork for a better understanding of patient views on medical confidentiality.

DESIGN: Studies were found by searching MEDLINE, BIOETHICSLINE, and selected bibliographies. Articles concerning physician perspectives or implications of legal and administrative regulations were excluded. Only peer-reviewed journal articles reporting original research on patients' confidentiality views and conduct were included.

MAIN RESULTS: Many patients are unaware of or misunderstand their legal or ethical right to medical confidentiality protections, which leads them to both over- and underestimate confidentiality protections. The possibility that medical information might be revealed, intentionally or not, to acquaintances in a clinic or other social community troubles patients as much as information release to insurers or employers. A significant minority of patients distrust confidentiality protections, leading some to report that they delay or forgo medical care. If doubtful that confidentiality will be upheld, patients will act independently to protect information.

CONCLUSIONS: Our review found a wider variety of understandings and beliefs about medical confidentiality among patients than are often indicated in the writings of practitioners or legal experts. As medical confidentiality regulations evolve, these differences need to be recognized and accounted for in interactions between practitioners and patients.

KEY WORDS: review; medical confidentiality; patient attitudes; privacy; biomedical ethics.

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Medical confidentiality, despite its diminished state, remains important to doctors and patients.¹ Effective treatment requires accurate information. Patients are most likely to provide this information when they are not worried about public exposure. Organized medicine has begun to take seriously the need to respond officially to

patient concerns.^{2,3} An AMA task force has issued guidelines for health care organizations and experts have emphasized the urgent need to take seriously these patient concerns.^{2,3} The federal government has sought to reinforce deteriorating confidentiality protections by limiting some secondary uses of medical information.⁴ At the same time, however, new regulations permit or simplify access to medical information for insurers, practitioners, researchers, and law enforcement.⁴ Whether the combined effects of these provisions will be to increase, decrease, or bypass patient confidentiality concerns is unpredictable. A more certain consequence may be that patients will be confused about their rights to, and the scope of, medical confidentiality protection.

Guiding patients through these changes and preserving the benefits of medical confidentiality will not be easy. A greater awareness of how patients understand medical confidentiality and what they are likely to do when they believe confidentiality protections are inadequate is essential. A shift in perspective can facilitate the process. Instead of analyzing medical confidentiality from the physician's perspective as a professional and bureaucratic responsibility, we look at how patients understand and use it. However, although patient interests are at the core of medical confidentiality policy, patient views are at the margins of scholarly attention. This review has collected what research is available and analyzes it to inform physicians about important, and some unexpected, patient concerns.

METHODS

To develop a comprehensive account of patient views of medical confidentiality, we searched MEDLINE (1966 to March 2001) and BIOETHICSLINE (1980 to March 2000), to identify studies of patient attitudes, beliefs, and concerns. We used the National Library of Medicine medical search headings (MeSH) term *confidentiality* crossed with MeSH terms for sensitive medical conditions, including *substance abuse*, *sexually transmitted disease (STD)*, *domestic violence*, *birth control*, *contraception*, *abortion*, *infertility*, *eating disorder*, *bulimia*, *anorexia*, *BRCA*, *HIV/AIDS*, *psychiatry*, *mental health*, and *genetic testing*, and crossed with terms for research methodologies, including *questionnaire*, *data collection*, *research study*, *interview*, *KAP*, *analysis of variance*, and *computers*. To locate additional articles,

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citations were reviewed and experts in medical confidentiality consulted.

The majority of the 5,746 articles identified by this search examined confidentiality from the practitioner's perspective rather than the patient's,⁵ addressed the need for confidentiality reforms rather than current practice,⁶⁻⁸ discussed confidentiality issues relevant only to research subjects, or reviewed regulations or laws governing medical confidentiality,⁹⁻¹² and were excluded from review.

The 347 articles whose abstract or title indicated that they fit our patient-focused criteria were read by SM, NLJ, and PS (at least 2 read each one). Two hundred thirty were excluded because they were opinion pieces, were not based on research with patients (or potential patients), or concerned confidentiality outside of the clinical encounter. An additional 7 were excluded because they addressed dental patients. This left 110 studies that met our criteria. The variable quality and research designs in this set did not permit a meta-analysis. Instead, we grouped the papers into 4 categories relevant to physicians responsible for patient confidentiality. The first 2 categories are general and concern patient knowledge and expectations of confidentiality: 1) *understanding and awareness*, or what patients think medical confidentiality is, and their awareness of its ethical and legal basis; and 2) *limits of access*, or who should be allowed access to medical information. The third and fourth categories concern how patient confidentiality worries influence their conduct in medical interactions: 3) *effect on seeking care*, or how confidentiality concerns affect patients' decisions to seek medical care; and 4) *effect on disclosure*, or how confidentiality concerns influence what patients will discuss with providers, once care is sought.

Table 1 lists the 110 articles grouped by population and topic, and indicates the study methodology, number of subjects, and which of the 4 categories the study addresses. We turn now to discuss these themes and studies in more detail.

RESULTS

Patient Understandings and Awareness of Confidentiality

Only a handful of articles directly addressed patient understanding of medical confidentiality or their awareness of its ethical and legal basis. Regarding patient understandings of medical confidentiality, 3 studies of children (ranging in age from 6 to 18) showed that nearly all of the subjects could choose or generate an approximate definition of medical confidentiality, when researchers used words such as *secret* or *trust*, along with, or instead of, *confidential*.¹³⁻¹⁵ Common responses included, "It's private and no one should know,"¹³ or "Just between you and me."¹⁵ In contrast, 3 studies of adults reported that subjects often had difficulty explaining medical confidentiality.¹⁶⁻¹⁸ For example, in a study of 76 adult

psychiatry patients, slightly more than half responded with "I don't know" or "I don't understand" when asked to provide a definition of the word confidentiality.¹⁷ Although these studies are of limited generalizability, 2 implications merit attention. First, there appears to be a group of patients who are unclear about the basic intent or function of medical confidentiality. Additional research below confirms this observation. Second, while the concept to which medical confidentiality refers is familiar to some, the word may not be; to wit: the better performance of the children was elicited using words such as *secret* or *trust*. This suggests that clinicians should assess the phrases they use when discussing confidentiality with patients.

While adolescents may be able to define confidentiality, many are apparently unfamiliar with physicians' ethical obligation and their own legal right to medical confidentiality. For example, a 1997 study found that 35% of 490 Massachusetts adolescent subjects did not believe or know that HIV tests results were kept confidential, and 19% falsely believed that automatic partner notification followed a positive test result.¹⁹ Four additional studies,¹³⁻¹⁵ and a fifth on homosexual youth²⁰ confirmed that adolescents are uninformed about routine confidentiality protections. No studies reviewed investigated whether adolescents understood the limits on confidentiality imposed by laws that require reporting physical or sexual abuse, and reporting of persons believed to be a danger to themselves or others.^{21,22}

Research on adult awareness of medical confidentiality's legal and ethical basis is less useful as it is dated or is exclusive to mental health patients. Furthermore, the mental health patient data show no clear pattern, with 1 study showing high understanding of a physician's obligation to protect patient information²³ and 2 others reporting opposite findings.^{24,25} Focus group research with abused women revealed that although a substantial minority of subjects understood their right to confidentiality, these same subjects were ignorant of state law requiring health care personnel to report suspected cases of physical or sexual abuse.²⁶

Studies addressing consent to release of medical information reveal similar gaps in patient awareness. Two studies reported that patients signed release-of-information statements because they believed they had no choice,^{27,28} and in a third, half of 195 general medicine patients signed release statements without realizing they had done so.²⁹ One researcher's recognition of this problem led to a study of 1,620 mental health patients in which researchers asked subjects at 2 clinics to fill out release-of-information forms without mentioning whether signing the form was optional or required. All of these clients signed the form. In contrast, 59% of subjects at a third clinic, who were told that they could refuse to sign without losing their right to service, did not sign.²⁷ Studies also show that patients with sensitive medical information might be more likely to understand the implications of

Table 1. Research on Patient Perspectives of Medical Privacy

Population/Topic	Ref #	Method	N	Understanding/ Awareness of Confidentiality	Beliefs About Limits of Access to Information	Effects of Confidentiality Concerns on Seeking Care	Effects of Confidentiality Concerns on Disclosure
Adolescents							
Messenger CB, McGuire JM (1981)	[13]	Interview	39	X	X		
Ginsburg KR, et al. (1997)	[15]	FG/Survey	215	X	X		
Cheng TL, et al. (1993)	[14]	Survey	1,295	X	X	X	
Samet JH, et al. (1997)	[19]	Survey	490	X		X	
Allen LB, et al. (1998)	[20]	Survey	102	X			X
Ford CA, et al. (1997)	[21]	Survey	562	X		X	X
Fisher CB, et al. (1996)	[36]	Survey	147		X		
Croft CA, Amussen L (1993)	[46]	FG	800		X		
Cogswell BE (1985)	[47]	FG	747		X		
Boekeloo BO, et al. (1996)	[48]	Survey	221		X		
Schuster MA, et al. (1996)	[49]	Survey	2,026		X		
Friedman LS, et al. (1993)	[69]	Survey	101			X	
Oppong-Odiseng AC, Heycock EG (1997)	[87]	Interview	253			X	
Klein J, et al. (1998)	[92]	Interview	259			X	
Holmberg LI, Wahlberg V (2000)	[89]	Interview	18			X	
Marks A, et al. (1983)	[90]	Survey	649			X	
Kapphahn CJ, et al. (1999)	[91]	Survey	5,067			X	
Klein JD, et al. (1999)	[92]	Survey	6,728			X	
Keyl PM, et al. (1996)	[93]	Survey	280			X	
Sugerman S, et al. (2000)	[94]	Survey	356			X	
Resnick M, et al. (1980)	[95]	FG	>800			X	X
Chamie M, et al. (1982)	[96]	Survey	9,468			X	
Bar-Cohen A, et al. (1990)	[97]	Survey	144			X	
Ginsburg KR, et al. (1995)	[98]	Survey/FG	6,821			X	X
Santelli J, et al. (1996)	[99]	Survey	3,258			X	
Warr D, Hillier L (1997)	[100]	Survey/FG	1,168			X	
Paperny DM, et al. (1990)	[112]	Survey	4,137				X
Lewis EC, Warman RE (1964)	[116]	Survey	164*				X
Woods KM, McNamara JR (1980)	[117]	RCT	60				X
Kobocow B, et al. (1983)	[118]	Interview	90				X
Thrall JS, et al. (2000)	[119]	Survey	2,224				X
Cancer							
Patno KM, et al. (1988)	[37]	Survey	100		X		
Roberts FD, et al. (1993)	[38]	Interview	108		X		
Winter PR, et al. (1996)	[39]	Survey	376		X		
Computer use							
Carman D (1995)	[33]	Interview	39		X		
Ridsdale L, Hudd S (1994)	[58]	Interview	30		X		
Als AB (1997)	[61]	Interview	12		X		
Pringle M, et al. (1984)	[62]	Survey	350		X		
Rethans JJ, et al. (1988)	[63]	Survey	390		X		
Liaw ST (1993)	[59]	Survey	315		X		
Navaline HA, et al. (1994)	[60]	Interview	68		X		
Ornstein S, Bearden A (1994)	[64]	Interview	16		X		
Bendtsen P, Timpka T (1999)	[65]	Survey	57		X		X
Paperny DM, et al. (1990)	[112]	Survey	4,137				X
Locke SE, et al. (1994)	[114]	Survey	272				X
Gerbert B, et al. (1999)	[115]	Survey	1,952				X
Gerbert B, et al. (1998)	[113]	Survey	459				X
Genetic testing							
Benkendorf JF, et al. (1997)	[42]	Survey	238		X		
Decruyenaere M, et al. (1993)	[43]	Survey	169		X		
Phillips K, et al. (2000)	[44]	Survey	134		X		

(Continued)

Table 1. (continued)

Population/Topic	Ref #	Method	N	Understanding/ Awareness of Confidentiality	Beliefs About Limits of Access to Information	Effects of Confidentiality Concerns on Seeking Care	Effects of Confidentiality Concerns on Disclosure
Genetic testing							
Appelbaum-Shapiro S, et al. (2001)	[45]	Survey	55		X		
Goelen G, et al. (1999)	[50]	RR	45		X		
Tessaro I, et al. (1997)	[51]	FG	66		X		
Wilcke JT, et al. (1999)	[52]	Survey	1,609		X		
Lerman C, et al. (1996)	[54]	Interview	279		X	X	
Durfy S, et al. (1999)	[53]	Survey	537		X		
Geller LN, et al. (1996)	[101]	Survey	917			X	X
Lapham EV, et al. (1996)	[102]	Survey	332			X	
Burgess MM, et al. (1997)	[103]	Case Study	2			X	
HIV/AIDS							
Samet JH, et al. (1997)	[19]	Survey	490	X		X	
Shaw M, et al. (1996)	[35]	Survey	662		X		X
Curtis JL, et al. (1989)	[41]	Survey	868		X		
Schuster, et al. (1996)							
Navaline HA, et al. (1994)	[60]	Interview	68		X		
Fehrs LJ, et al. (1988)	[66]	Survey	1,148			X	
Kegeles SM, et al. (1990)	[67]	Survey	180			X	
Centers for Disease Control (1993)	[68]	RR	9,446			X	
Friedman LS, et al. (1993)	[69]	Survey	101			X	
Hirano D, et al. (1994)	[70]	RR	15,583			X	
Meyer PA, et al. (1994)	[71]	RR	57,212			X	
Phillips KA, et al. (1995)	[72]	Survey	10,630			X	
Hertz-Picciotto I, et al. (1996)	[73]	RR	71,181			X	
Kassler WJ, et al. (1997)	[74]	RR	10,750			X	
Paringer L, et al. (1991)	[75]	RR	16,907			X	
DePhilippis D, et al. (1992)	[76]	Survey	196			X	
Phillips KA (1994)	[77]	RR	21,831			X	
Osmond DH, et al. (1999)	[78]	Survey	388			X	
Woods WJ, et al. (1999)	[79]	Interview	130			X	
Morse EV, et al. (1991)	[85]	Survey	40			X	
Beedham H, Wilson-Barnett J (1995)	[80]	Interview	85			X	
Moneyham L, et al. (1996)	[81]	FG	19			X	X
McDonald R, et al. (1998)	[82]	Survey	79			X	
Erwin J, Peters B (1999)	[83]	FG	44			X	X
Petchey R, et al. (2000)	[84]	Interview	20			X	X
Berger BSG, et al. (1999)	[86]	Interview	251			X	
King MB (1988)	[111]	Interview	192				X
Marks G, et al. (1995)	[105]	Survey	632				X
Madge S, et al. (1999)	[104]	Survey	870				X
Wadsworth E, McCann K (1992)	[109]	Interview	263				X
Mansfield SJ, Singh S (1989)	[110]	Interview	100				X
Kochen MM, et al. (1991)	[106]	Survey	394				X
Gill SK, et al. (1992)	[107]	Survey	174				X
Perry S, et al. (1990)	[108]	Interview	40				X
Locke SE, et al. (1994)	[114]	Survey	272				X
Gerbert B, et al. (1998)	[113]	Survey	459				X
Banks HD, et al. (1993)	[121]	Survey	361				X
Mental health							
Messenger CB, McGuire JM (1981)	[13]	Interview	39	X	X		
Lindenthall JJ, Thomas CS (1982)	[16]	Survey	76	X	X	X	

(Continued)

Table 1. (continued)

Population/Topic	Ref #	Method	N	Understanding/ Awareness of Confidentiality	Beliefs About Limits of Access to Information	Effects of Confidentiality Concerns on Seeking Care	Effects of Confidentiality Concerns on Disclosure
Mental health							
McGuire JM, et al. (1985)	[17]	Survey	76	X	X		
Claiborn CD, et al. (1994)	[18]	Survey	96	X			
Appelbaum PS, et al. (1984)	[23]	Interview	58	X	X		
Schmid D, et al. (1983)	[24]	Interview	30	X	X		
Weiner MF, Shuman DW (1984)	[25]	Survey	191*	X			X
Rosen CE (1977)	[27]	Survey	1,620	X			
Kinzie JD, et al. (1985)	[28]	Survey	32	X	X		
VandeCreek L, et al. (1987)	[32]	Survey	116		X		
Trippitelli CL, et al. (1998)	[34]	Interview	90		X		
Lewis EC, Warman RE (1964)	[116]	Survey	164*				X
Woods KM, McNamara JR (1980)	[117]	Survey	60				X
Primary care/general							
Rodriguez MA, et al. (1998)	[26]	FG	51	X	X		X
Lorge RE (1989)	[29]	Survey	195	X	X		
Yawn BP, et al. (1998)	[30]	RR	16,000	X			
Merz JF, et al. (1999)	[31]	RR	240	X	X		
Carman D (1995)	[33]	Interview	39		X		
Lindenthall JJ, Thomas CS (1982)	[40]	Survey	283*		X		
Weiss BD (1982)	[55]	Survey	177		X		
Weiss BD, et al. (1986)	[56]	Survey	385		X		
O'Flynn N, et al. (1997)	[57]	Survey	335		X		
Ridsdale L, Hudd S (1994)	[58]	Interview	30		X		
Als AB (1997)	[61]	Interview	12		X		
Pringle M, et al. (1984)	[62]	Survey	350		X		
Rethans J-J, et al. (1988)	[63]	Survey	390		X		
Liaw ST (1993)	[59]	Survey	315		X		
Ornstein S, Bearden A (1994)	[64]	Interview	16		X		
Bendtsen P, Timpka T (1999)	[65]	Survey	57		X		X
Gerbert B, et al. (1999)	[115]	Survey	1,952				X
Smith EM, et al. (1985)	[120]	Survey	2,345				X
McDaniel TF, et al. (1995)	[122]	Survey	107				X

* Number includes comparison population in addition to patients.
FG, focus group; RCT, random controlled trial; RR, record review.

authorizing release of their medical information³⁰ or to refuse its release.³¹

Patient Beliefs About Access to Medical Information

The literature addressing patient beliefs about access to medical information poses several questions, including: 1) whether patients approve of their physicians sharing medical information with other physicians; 2) under what circumstances patients might sanction breaches of confidentiality; and 3) patient opinions about sharing medical information with employers, families, and third parties.

Across a wide range of medical settings, including general practice, cancer care, and genetic testing, research has found that most patients recognize physicians' need to share patient information with one another,^{17,23,24,32-34}

although 1 study suggests that HIV patients may be less likely to approve information sharing.³⁵

Patient conviction that access to medical information should be restricted to people involved in patient care is upheld by several studies examining confidentiality breaches. Patient opinions about when confidentiality can be broken without their permission vary by patient population, information content, and to whom the information would be given. Adolescents based acceptance of breaches on the perceived severity of the problem, with situations such as physical or sexual abuse and suicide threats justifying disclosure to appropriate officials.^{13-15,36} Battered women participating in focus groups agreed that breaching confidentiality might be acceptable, but only in a situation in which the woman herself wanted relief from the burden of disclosure.²⁶ Of 100 parents of pediatric cancer patients surveyed in 1998, the vast majority sanctioned information disclosure without consent when done to help

families in similar situations.³⁷ In general, while patients may not be aware of specific laws protecting medical information, they do expect that it will be kept confidential and that this confidentiality will be breached only in exceptional situations that threaten the welfare of the patient.^{38–40}

However, while accepting information sharing among doctors, patients in numerous studies rejected release of information to employers, family, and third-party payers.^{15,17,24,28,29,31,32,34,41–45} One study of primary care patients found that many of those who agreed to sign forms allowing their practitioner to release medical information to an insurance company did so only because they erroneously believed that their practitioner would withhold sensitive information.²⁹

Adolescents are particularly preoccupied that health practitioners keep discussions private from parents, teachers, and friends.^{13,14,46–49} In a survey conducted of 2,026 California high school students, only 44% trusted that their physician would keep a sexually transmitted disease secret from their parents. Of those who knew of a state law prohibiting physicians from informing parents of adolescents' STDs, there was only a slight rise in reported levels of trust to 54%.⁴⁹

Studies on genetic testing report contrasting findings about the appropriateness of patients revealing genetic test results to family members versus physicians doing so.^{50–52} Research generally finds high levels of support for the former,^{43,45,51} but not the latter.^{42,53} For example, 97% of 200 Jewish women in a telephone survey on knowledge and attitudes about genetic testing said patients themselves had a duty to inform at-risk family members of genetic disposition to preventable diseases; however, only 22% agreed that a physician had a duty to seek out and inform family members.⁵⁴

Several studies examined patient concerns about confidentiality within the medical setting itself. The majority of adults surveyed in 3 studies indicated that they expected nurses and medical students to have limited access to patient medical records,^{55–57} while subjects in 2 other studies maintained that office staff did not, or should not, have access at all.^{33,35} In addition to preferring limiting access to only certain members of a medical team, a survey of 177 family practice patients reported that many did not anticipate that their personal cases would be presented at large conferences (31%), shared with physician's spouses (83%), or discussed at parties (82%).⁵⁵ Adolescents participating in focus groups worried that nurses and other staff exchanged patient information on occasions unrelated to patient care and saw it as the possible means by which private medical information might reach parents.¹⁵

Medical record computerization studies suggest this technology sometimes exacerbates confidentiality concerns. Five studies of primary care populations found that one third to one half of respondents were concerned that computerized systems allow too many people easy access

to records.^{33,58–63} However, only a small number of patients reported that computerization concerns were strong enough to lead them to withhold information from a physician or to consider changing physicians.^{64,65}

The Effect of Confidentiality Concerns on Patients' Willingness to Seek Care

Studies examining willingness to seek HIV testing outnumber all other studies about how confidentiality concerns might influence care seeking. Nine of 20 studies on this topic examined patient preferences for anonymous testing (no link between test result and individual's name) versus confidential testing (test result linked to individual's name). The earliest, a 1988 survey of 1,148 first-time patients seeking HIV testing in Oregon public health clinics, reported that the introduction of anonymous testing increased testing 125% among gay men, 56% among prostitutes, and 33% among persons with high-risk sexual partners.⁶⁶ Subsequent studies confirmed the finding that anonymous HIV testing attracts more testers than confidential testing.^{67–74}

Underscoring preference for anonymous testing, 4 studies conducted between 1988 and 1996 reported substantial numbers of potential testers who would forego HIV testing altogether if only confidential testing were offered.^{66,67,72,73} Contact tracing also deterred some high-risk individuals from testing.^{75–78} However, a 1999 study of 130 high-risk males seeking testing at a San Francisco HIV clinic found that an explanation of the public health advantages of contact tracing can increase slightly the number of people willing to test.⁷⁹ Finally, several studies reported that fear of being seen entering HIV clinics^{80–84} or being seen taking HIV medication⁸⁵ was sufficient to deter some people from seeking care.

While anonymous testing seems to increase the number of willing HIV testers, a recent study of 251 seropositive male clients of Missouri public health clinics suggested a potentially troubling consequence of heightened privacy concerns.⁸⁶ Interviews with these HIV testers found that those who had tested anonymously in the past were less likely than those who had tested confidentially to have notified partners or primary providers of their HIV status, or to have accepted care coordination.

Adolescents rank alongside those seeking HIV testing in the extent to which confidentiality concerns influence decisions of when and where to seek medical care.^{14,87–89} Inadequate trust in private physicians to withhold information from parents is frequently reported as a cause of unmet health needs.^{90–93}

Rather than risk information disclosure to parents, 25% of 1,295 high school seniors surveyed in 1992 reported that they would forego care altogether.¹⁴ Those preferring not to forego care sought it elsewhere. Of 356 female adolescent patients at a Planned Parenthood clinic, 24% reported not trusting their primary care doctor to keep

confidential conversations about sexual activity, 35% reported the same concern for STDs, and 40% for pregnancy.⁹⁴ Greater trust in adolescent-specific health care services to protect confidentiality leads adolescents to seek care in these settings.^{14,21,90,95-99} Authors of a survey on HIV-related knowledge and behavior given to 490 randomly selected Massachusetts adolescents, ventured that the large number of subjects who reported getting HIV testing through a blood bank might be explained by teenage ignorance of where to go for confidential health care.¹⁹ Even when they know where to seek care, adolescents report that fear of being seen entering a doctor's office or purchasing condoms at a drug store stops some from doing so.¹⁰⁰

Limited data suggest that some mental health patients also forego care due to confidentiality fears.¹⁶ Likewise, fears about insurance and employment discrimination subsequent to genetic testing hinder some people at risk from seeking this service. Individuals reported trying to protect the confidentiality of genetic information by paying out-of-pocket for testing, obtaining insurance policies prior to genetic testing, or obtaining anonymous genetic testing.^{54,100-103}

The Effect of Confidentiality Concerns on Patients' Willingness to Disclose Information

Among HIV positive patients who seek care, confidentiality worries lead some to withhold vital information from clinicians.^{84,104-111} Many who withheld their diagnosis from doctors did so because they did not trust the practitioner or the clinical setting to be able to keep the information confidential,⁸¹ or they feared refusal of treatment or discrimination.^{83,84,105,111}

In response to studies indicating patient unwillingness to disclose an HIV positive diagnosis due to confidentiality concerns, recent research has surveyed patients about more effective methods for protecting HIV-related patient information in primary care clinics. For example, in one questionnaire study of HIV positive patients attending a genitourinary clinic, 34% of those who objected to the clinic staff knowing their status said that they would be more willing to disclose this information if the clinic were to adopt and clearly advertise a nondiscrimination policy.³⁵ Other studies report on the value of refining methods to screen high-risk behavior, including using computers, in an effort to generate higher rates of risk-behavior disclosure.^{65,112-115}

Studies on adolescents confirm that they too withhold information from clinicians due to confidentiality concerns.^{20,21,95,116-119} Censored topics include sexual orientation, drug use, and depression. For some adolescents, withholding information is a routine protective strategy when deciding to seek care. One survey of 6,821 adolescents found that, on average, adolescents ranked confidentiality concerns a distant 11th in a list of deterrents to seeking medical care. When a subset of these

original subjects were subsequently asked to react to this finding, several ventured that they could protect their own confidentiality simply by remaining silent.⁹⁸

Additional populations reporting withholding information due to fears that confidentiality would be inadequately protected include blood donors, mental health patients, people seeking genetic testing, and bisexuals and lesbians seeking gynecological care.^{25,26,101,120-122}

DISCUSSION

The patient's perspective on medical confidentiality has been studied primarily within vulnerable populations, including mental health patients, seekers of genetic testing or HIV testing, and adolescents. Research has focused on practical circumstances facing these populations, such as preferences for anonymous versus confidential HIV-positive testing, rather than inquiring more broadly into the confidentiality worries of patients. Perhaps for this reason, it is still the exception in confidentiality research to refer to or build on prior research. Generalizations from these studies are hindered by their highly specific research questions, the variety of populations studied, and the frequent incommensurability or inadequacy of research methods and design.

Nonetheless, 4 summary points can be drawn from this review of patient views on medical confidentiality. First, patients are confused about basic ethical, legal, and practical limits on medical confidentiality. For example, the word "confidential" may not be understood by all patients,¹⁶⁻¹⁸ and many seem confused over which medical information is protected, and how.^{19,20,24-29} As a result, patients often either underestimate or overestimate the extent of confidentiality protections, especially concerning preferences or assumptions about third-party payers' access to medical information.^{17,24,27-30,32,34,42} Underestimating confidentiality protections leads adolescents and people at risk for HIV to deprive themselves of needed care for fear that information will be necessarily and automatically released.^{14,66,67,72,73,90-93}

Second, patients' confidentiality concerns are often more local and specific than the concerns that policies and new federal regulations address. For example, patients worry that someone from their community will witness them entering or exiting a clinic.^{80-83,85} Other patients expressed the opinion that clinic staff ought not live in the community.³³ Some assume that doctors will discuss patient cases with the nurse, and that both doctor and nurse might take patient medical information beyond the walls of the clinic by sharing it with the patient's relatives, with their own family and friends at social gatherings, or at conferences.^{35,55-57} Patient objection to the practice of sharing information with nurses or office staff then is based not on a rejection of the medical or bureaucratic justification of the need to share details of a case, but on potential consequences of that information traveling to the more intimate realm of a patient's social community.

This emphasis on personal consequences helps explain the third finding as well, which is that patients prefer that medical information be used exclusively for treatment. Studies showed that patients grasp the need for and benefit of sharing medical information. Some studies, indeed, indicated that under certain circumstances, patients approved disclosures made without a patient's authorization.^{26,37} Patient approval of select disclosures, coupled with patient rejection of routine release of information to insurance companies for reimbursement may suggest that some patients recognize medical information only as a vehicle to serve the direct medical needs of its owner.^{14-16,23,36,38,39,40} Thus, reports that adolescents avoid care rather than risk parents getting access to their medical information,^{14,90-92} and reports that adolescents may countenance a direct breach of confidentiality if done to help a patient get the care he or she needs may not be contradictory. Instead, they may reflect the belief that the sole function of medical information is good medical care, care that may or may not involve one's parents (or other authorities). Patients who resist information release therefore seem not to resist it on principle, or even based on whether the release is sanctioned or unauthorized. Their concern is rather with the circumstances surrounding the release.

Taken together, these 3 findings explain much about the fourth and most alarming finding, that patients will delay or forego treatment, or alter stories about symptoms and onset of illness, to be sure those details never emerge publicly. Adolescents,^{14,21,92-100,118,119} battered women,²⁶ people with HIV or those at high risk for HIV,^{80-83,107,111} women undergoing genetic testing,^{54,101,102} and mental health patients^{16,25} all reported at least occasional instances when they chose not to seek treatment because of confidentiality concerns, or decided to withhold information during clinical interactions for the same reason. Such conduct is precisely what medical confidentiality protections are intended to prevent. Patients take independent actions to protect their medical information for several reasons, including ignorance or misinformation about protections they already have or may invoke, and fears that no protection is complete enough to stop the flow of private information from the clinic into their social community.

These studies suggest that current changes in medical confidentiality legislation fall short of addressing patient fears. While they address institutional or bureaucratic circulation of information, which is of concern to patients, they ignore the privacy concerns of patients that emerge from the social or clinical context of care. To provide confidentiality protections that address these concerns, additional research attention to the patient's perspective is called for, and might include the following: 1) investigation of the general patient population in comparison to vulnerable populations as a way to gauge the extent of unmet patient needs; 2) examination of patient fears about inadvertent disclosure of medical information, beyond recognized concern with implications

for health insurance, employment, and discrimination; and 3) creation of environments that encourage patients to feel protected. Current trends in health care seem to have set in motion a seemingly endless stream of financial and regulatory changes that force patients to frequently change clinics and doctors. In this context, care must be taken to stay mindful of the need for providing a protective and private treatment setting so that patients can pursue the care they need unhindered by fears of exposure.

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